for scoliosis surgery in hospitals in Ireland, had increased from 230 at the end of September 2016\textsuperscript{78} to 236 at the end of December 2016.\textsuperscript{79} In January 2017, the HSE announced as key achievements of its waiting list action plan 2016\textsuperscript{80} that:

- 24 paediatric scoliosis patients waiting more than 18 months had either been treated or would have a treatment plan in the Blackrock Clinic in Dublin within the coming weeks; and all other paediatric scoliosis patients breaching 18 months had a treatment plan at Crumlin;
- 23 adolescent scoliosis patients breaching 18 months were clinically reviewed in the Mater Misericordiae University Hospital’s spinal unit. Any patients requiring surgery had either been treated or were scheduled for treatment that month.

According to the Minister for Health, the focus of the new waiting list action plans for 2017 is to ensure that by the end of October 2017, no patient will be waiting more than 15 months on the inpatient/day-case waiting list, or on the outpatient waiting list.\textsuperscript{81} It has been documented that some children with scoliosis are waiting for over two years for their first appointment, and in some cases are not getting post-operative reviews for three years.\textsuperscript{82} The OCO is of the view that child-specific waiting lists should be published\textsuperscript{83} for all healthcare services in Ireland. Targets for maximum waiting times for out-patient appointments should be established with reports which monitor these targets published quarterly.

The Minister for Health, Simon Harris, has also announced that the new operating theatre for the treatment of scoliosis will open at Crumlin Children’s Hospital in April 2017 and will carry out 194 spinal operations this year.\textsuperscript{84} However, the Hospital is still in the process of a recruitment drive to attract new theatre nurses with the necessary paediatric training and an orthopaedic surgeon post in Crumlin hospital will only be filled in June.\textsuperscript{85} The Minister has confirmed that children on waiting lists must be treated within the scheduled wait time or have their case outsourced to private clinics for treatment.\textsuperscript{86} Minster Harris recently stated in the Dáil:

‘....even as we speak, HSE officials are in Stanmore in the UK looking at the possibility of utilising a facility there to help to deal with....a backlog in terms of procedures, especially in treating scoliosis. We can open an additional theatre here or there or hire additional consultants and use other hospitals...to provide support. However, if we are serious about radically reducing the waiting times, we are going to need to do something above and beyond the norm to get the lists to a level where they are sustainable.’\textsuperscript{87}

Research and international best practice, unequivocally show that delays in surgery for children with scoliosis who qualify for surgical

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\item \textsuperscript{83} Figures from the National Treatment Purchase Fund indicate that at the end of January 2017, 3,289 children were waiting for over 18 months for an outpatient appointment. However, it appears that accessible, accurate and comprehensive information in relation to waiting lists for children accessing health services in Ireland are currently unavailable in the public domain. See Dáil Debate, Wednesday, 8 March 2017 at https://www.kildarestreet.com/debates/?id=2017-03-08a.429 (accessed 13/03/2017).
\item \textsuperscript{85} Dáil Debate, Wednesday, 8 March 2017 at https://www.kildarestreet.com/wrans/?id=2017-03-08a.219&s=speaker%3A414 (accessed 13/03/2017).
\item \textsuperscript{87} Dáil Debate, Wednesday, 8 March 2017 at https://www.kildarestreet.com/debates/?id=2017-03-08a.429 (accessed 13/03/2017).
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treatment are associated with increased operative time, longer fusion levels, need for combined procedures, and potential for complications.88 Furthermore, Irish-led research shows that children with idiopathic scoliosis and a curvature over 70 degrees, often as a result of lengthy surgical waiting lists, do not do as well post-surgery as those under 70 degrees.89 These cases are associated with increased surgical complexity and higher cost of surgical treatment, as well as delayed postoperative return to school or other full-time education.90

There have been significant delays in publishing the promised HSE action plan on scoliosis. We understand that the HSE will deliver on this commitment in the coming weeks.91 The HSE director general Tony O’Brien has committed that by the end of this year, no child will wait longer than four months for a paediatric scoliosis procedure. This report makes a number of recommendations which should be taken into account by Government to ensure access to timely access to treatment for scoliosis patients. However, the recommendations also place this issue in the broader context of the child's right to the highest attainable standard of health.

In accordance with Article 24 CRC, every child in Ireland waiting for paediatric orthopaedic surgery for scoliosis is entitled to the enjoyment of the highest attainable standard of health and to facilities for the treatment of this illness and for the rehabilitation of their health. In particular, the Government is under an obligation to adopt a child rights-based approach to all decisions affecting the health and development of children with scoliosis and to take special measures to ensure the implementation of their rights, including through the allocation of sufficient and sustainable resources and the development of child-friendly healthcare services.

However, the lived experiences of this vulnerable group of children over the last decade illustrate how the lack of adequate Government action has led to consistent breaches of their right to health. The constant pain associated with the condition, the deteriorating effects of an increasing curvature of the spine, the growing visible physical deformity, the emotional and mental distress suffered and in some cases the inability of children’s internal organs to cope has directly and negatively affected these children’s right to health in and of itself (Article 24 CRC). Their enjoyment of other human rights has also been affected, including their right to a standard of living adequate for their physical, mental, spiritual, moral and social development (Article 27 CRC), their right to education (Article 28 CRC), their right to play and recreational activities (Article 31 CRC), and in some cases their right to survival and development (Article 6 CRC).

Many children with scoliosis in Ireland have been denied orthopaedic spinal surgery for up to 18 months because of factors that range from a lack of resources and operational capacity, to a lack of availability of anaesthetists, theatre nurses, and funding from the HSE. The involvement of the OCO with complaints over a sustained period of time has found that, despite a number of short-term measures and some temporary improvements in waiting list times, the number of patients waiting significant periods of time for scoliosis treatment has continued to increase.

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As outlined in this report, while initiatives have been put in place as a response to the waiting lists, these have not successfully addressed the long term human and capital resource issues that continue to impact on the ability of those involved to plan and deliver successful operations, in a timely manner, which would best meet the needs of children with scoliosis. While short term initiatives have had some success, it is a matter of serious concern to the OCO that the longer term initiatives have not materialised, despite being identified a number of years ago. This situation is not in compliance with international obligations under Article 24 of the CRC.

It has been established that children are often affected in different ways from adults, both psychologically and physically, by violations of their right to health due to their stage of development. However, the testimonies and other information set out above confirm that the Government has failed to fully discharge its obligation to provide children with timely access to essential health services for the treatment of scoliosis. It has also been demonstrated that, in practice, such delays can result in children being left in limbo and can have long-term detrimental effects on their development and future capacity for autonomy.

The importance of transparent decision-making in how resources are rationed has become increasingly important in recent years. However, there has been reluctance in Irish law, policy and political debates to define economic, social and cultural rights, such as health care provision, as legal entitlements. Public policy and debate in the area of health must give consideration to providing a robust legal guarantee for equal access to healthcare. In February 2014, the Constitutional Convention recommended that socio-economic and cultural rights are provided express Constitutional protection. As far as this Office is aware, there has been no action taken by Government in relation to this recommendation to date.

The main argument put forward by the Oireachtas and the Courts against such Constitutional protection is the separation of powers doctrine - that the power to determine how the State collects and distributes revenue and resources is vested in the Oireachtas. However, Ireland has accepted the indivisible nature of all human rights at an international level and it is time to take these human rights obligations seriously. Guidance from UN Committees charged with monitoring
international treaties (such as the CRC), show that it is possible to frame legislative and Constitutional protection for such rights in a way that ensures they are closely aligned with the separation of powers doctrine.

The obligation to undertake all measures, to the maximum extent of available resources, to progress the full realisation of the children’s rights principles enshrined in the CRC has been interpreted as a call for prioritisation of children within the state budget so as to ensure appropriate levels of service delivery. The Special Rapporteur on Child Protection recently stated that ‘Ireland must “take all necessary measures” to improve healthcare services, including through increased public spending’. As outlined above, the Committee on the Rights of the Child has been very clear about the link between budgets and resources and the realisation of children’s rights. It has stated as follows:

Implementation of the human rights of children must not be seen as a charitable process, bestowing favours on children... No State can tell whether it is fulfilling children’s economic, social and cultural rights ‘to the maximum extent of available...resources’ as it is required to do under article 4 [of the CRC], unless it can identify the proportion of national and other budgets allocated to the social sector and, within that, to children, both directly and indirectly.

Accountability is also well established as an important principle of human rights. Ensuring accountability requires continuous monitoring by Government and Civil Society and includes budget analysis. While children are members of families and societies, we need to focus our attention on their distinct citizenship and ensure their inclusion in governance. Disaggregating specific spending for children would ensure that children are prioritised within the state budget so that policy commitments translate into the allocation of resources and appropriate levels of service delivery to protect children's rights.

Attention must be paid to the Committee’s Concluding Observations on Ireland and its most recent General Comment No. 19 on public budgeting for the realisation of children’s rights. While we acknowledge that it is essential that a balance be struck between competing demands on finite resources, the Government has recognised that children are entitled to special care, protection and assistance through its ratification of the CRC and other legal instruments and must implement its obligations in this regard. This is the basis for the recommendations made below specifically relating to children waiting for scoliosis treatment.

The powerful accounts from the young people who have shared their experiences of waiting for surgery in this report highlight the importance of the right of the child to have their views heard. However, there is also a duty to ensure that those views are taken into account in matters affecting them, in accordance with their age and maturity. It is important the children who are affected by scoliosis waiting lists are listened to and the negative effect this has had on their lives is taken into account by Government in formulating solutions. In the context of initiatives announced by Government most recently to address the backlog of children waiting for scoliosis treatment, it is important to listen to individual children and their families about the impact of having to travel abroad for this essential surgery, having regard to their particular circumstances.

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Section 6

Recommendations

1. The realisation of the right to health of children waiting for scoliosis paediatric orthopaedic surgery should be prioritised by Government action as a matter of urgency. No child with scoliosis should have to wait in excess of 4 months from when the need for surgery is clinically determined. This is in accordance with Government commitments recently made and in line with international best practice. Barriers to achieving this should be reviewed and eliminated.

2. The Department of Health should commission and publish a situational analysis of existing practices, issues and infrastructure for the delivery of paediatric scoliosis surgery services in Ireland. This situational analysis should:
   - assess the institutional capacity and the availability of human, financial, and technical resources. Specific deficits in resources should be identified.
   - Carry out a clinical review of services and set national and regional priorities for the treatment and aftercare of scoliosis and strategies for their achievement.
   - Budgeted action plans and operational strategies should be established and published with specific timeframes.

3. The Government and service providers should promote and facilitate the effective participation of children in improving their health, in taking part in decision-making related to their care, in planning health care activities and evaluating their results, according to their age and maturity.

4. National Standards of Practice, specific to respecting children’s rights within health services, should be developed and implemented. Child-specific waiting lists should be published for all healthcare services in Ireland. Targets for maximum waiting times for out-patient appointments should be established. Reports which monitor these targets should be published quarterly.

5. The Government should develop and implement a comprehensive and broadly-based national policy framework on child-friendly healthcare, taking account of international and European best practice and human rights standards. This should be done in consultation with children themselves and guided by the key principles of the CRC and by General Comment No. 15 on the right of the child to the enjoyment of the highest attainable standard of health.
6. To promote accountability for children’s health, this national policy framework must include a transparent mechanism to ensure that a cyclical process of planning, implementation, monitoring and evaluation takes place.

7. A national policy on child-friendly healthcare should include a specific strategy to build inter-sectoral alliances across the healthcare sector, to develop consensus and build and sustain momentum towards the implementation of children’s rights in healthcare settings. This collaborative network should include senior figures from the healthcare sector, a wide range of children’s health experts and professional groups, law and policy makers, healthcare managers, statutory agencies, patient and advocacy groups and inter-disciplinary researchers.

8. An expert group should be established across the healthcare sector to advise Government in relation to the development of this national policy and an accountability mechanism. The expert group should publish progress reports and report to the Joint Oireachtas Committee on Health.

9. The development of a national policy on child-friendly healthcare should be accompanied by awareness-raising measures, designed to promote children’s rights in healthcare among children, their families, practitioners, managers and policy-makers.

10. The Government should fully implement the Committee’s recommendations in its Concluding Observations on Ireland’s implementation of the CRC, particularly with regard to child-friendly budgeting. Although these recommendations apply to all budgetary decisions made by Government, the Department of Health should publish specific timelines for their implementation in the health sector.